

INSIDE STORY

Enslaved by the sandman — the shackles of narcolepsy

Sufferer relates his long tale of sleeping with the enemy

By Wayne Worcester
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I've never had trouble falling asleep.

I have dozed off on trains and snoozed until I missed not only my stop but my entire state. I have slumbered standing under a steaming shower and been shocked awake, looking like a candidate for a full-body Botox injections, when the water turned cold. My dentist has had to shake me awake to continue drilling my teeth.

It's an odd thing, being on the verge of unconsciousness all the time.

The government has a word for people like me: dangerous. We cause roughly 100,000 traffic accidents every year, according to the National Highway Traffic Safety Administration. In the process, we injure about 71,000 men, women and children, including ourselves, and send 1,550 people to early graves.

So when my own misadventures in wakefulness started to include unfriendly car horns waking me at traffic lights, I figured I'd better get professional help.

Dr. Marc Kawalick, medical director of the Sleep Disorders Center at New Britain General Hospital in Connecticut, had a ready smile and a vise for a handshake. His staff had told me to keep a sleep diary for a couple of weeks — a record of when I slept at night and when I felt tired by day. The doctor carefully reviewed it.

"There does seem to be a pattern," he said, "but we'll see." I took a test and was proud of scoring 23 out of 25 possible points on the Epworth Sleepiness Scale — until I learned it was like golf: the low score wins.

"And you snore, you said?" the doctor asked.

"It wakes even me sometimes." I replied.

One night, a few weeks later, I donned pajamas in one of the center's hospital bedrooms. An attendant pasted 22 electrodes all over my head, face, chin, chest, stomach and legs. Tests Kawalick ordered included a Multiple Sleep Latency Test, a monitoring of my wakefulness at two-hour intervals for the rest of the day.

It took three weeks for my results to be evaluated, more than enough time for me to ponder my lifelong problem — four decades' worth, going all the way back to high school in Keene, N.H., in the early 1960s.

Before my father died, he made me a maple desk so I'd have a place of my own to do schoolwork — and this I attempted, five nights a week, while listening to top-40 rock on my Magnavox radio.

I usually picked up the countdown in the low 30s; but by the time it reached the single digits, my head slumped onto the desk.

The truth that emerges through those years is this: Although I was reasonably bright, I never was going to excel at anything requiring prolonged concentration.

I fell asleep so regularly that teachers, family, most of the adults in my life, formed a chorus: "How can you be tired at your age? Know how you spell that? L-A-Z-Y."

I figured that everyone got as tired as I did and just handled it better. I was different, maybe inferior — too darned listless to have much hope of making my way in the world.

I wonder now what I might have learned had I been as awake as everyone else.

I wonder, too, if the depression and anger that complicated and soured relationships for most of my life were problems unto themselves or were rooted in my indescribable weariness.

"The government has a word for people like me: dangerous."

Narcolepsy victim Wayne Worcester, a professor of journalism at the University of Connecticut



I do know this: After weighing years of what had been, against intimations of what might have been, I feel sad and oddly removed from major parts of my own life.

My high school grades were good enough to get me into the state university. But my lecture notes con-

sisted of a few legible paragraphs followed by indecipherable scrawls that drifted off the page.

Joining 200 other students for a geology midterm, I awoke an hour later with no one left in the amphitheater but me and the scowling teacher.

My grades were not great. After two semesters, I slinked home in shame and went to work in a furniture factory. Through a haze of spray lacquer and sawdust, I got a quick glimpse of the rest of my life. So I saved as much as I could, and after a year returned to the university, chastened and determined.

This time I had a strategy: Take afternoon and evening classes, study subjects I loved, and study obsessively in odd hours of wakefulness. But I could not will myself to stay awake, even in my favorite cinema classes. When the lights went out, so did I.

On a date, I could be a laugh riot, and I'll leave it at that.

Then came the night that I drove a Ford Falcon station wagon straight off a New Hampshire highway, my foot a dead weight on the accelerator. I roared down an embankment, tore down 350 feet of barbed-wire fence and ripped out the undercarriage of the car on fieldstones.

I awoke to see the limb of an apple tree fill my headlights and made it to the floor just as the windshield blew straight into the back seat.

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Asleep: 1.4 minutes to reach REM? Wow!

Somehow, I stayed alive long enough, and learned enough, to attend the best journalism graduate school in the country and get a job at a fine daily newspaper.

News is all the time, so I could sleep for 14 hours and then do a full day's work, or sleep for four hours and grab a nap at my desk. As long as I got the story, no one cared. For the first time in my life, my inclination to function without regard for the clock was not a handicap.

Occasionally, though, there were glitches.

One evening, I was assigned to watch a televised address by President Carter with a Brown University political scientist.

The president spoke for about 20 minutes; I slept for 17.

Given the persistence of such episodes throughout the years, the results of the tests administered by Kawalick should not have been a surprise.

"You have narcolepsy," he said.

"Are you sure?" I asked.

The overnight test had proved, as medical people are inclined to say, "unremarkable." The daytime test was anything but.

I had not merely fallen asleep in the middle of the day — but more than once. I had skipped the first stage and plummeted straight into REM (rapid eye movement) sleep, the realm in which we dream.

Most people take from 16 to 90 minutes to get there. Slackers! I needed an average of only 1.4 minutes.

Narcolepsy. I already knew a bit about it — that it is neither fatal (except when combined with heavy machinery) nor curable, but that it carries with it an annoyingly understandable lack of sympathy.

"Well, what now?" I asked the doctor.

Scientists had recently discovered that narcolepsy appears to be caused by the lack of a chemical neurotransmitter in the hypothalamus at the base of the brain.

For now, Kawalick said, all one could do is try to control it.

He prescribed modafinil.

He also advised me to take a multivitamin and be ruthless about getting eight hours of sleep every night.

I followed the instructions, and the difference was remarkable.

I no longer felt tired all the time.

After nearly four years of taking the drug faithfully, I was certain I had my narcolepsy in hand.

That was an illusion.

On Feb. 21, 2003, I was alone in my Toyota in high-speed, 5 p.m. traffic on the outskirts of Providence, R.I. I don't remember getting drowsy. I do remember bolting upright when I hit the rear bumper of a pickup truck and began pushing it off the road. There were no injuries.

Seven weeks after the accident, I was able to pass a wakefulness test and resume driving.

Still, I am wary. I trust myself to drive only short distances, and only if I've napped. No exceptions.

Wayne Worcester is a professor of journalism at the University of Connecticut.

Respond to the following question on your warmup:

1. About how many traffic accidents in the U.S. are connected to narcolepsy?
2. How fast does Worcester slip into REM?
3. Can someone with narcolepsy legally drive? Explain.